

## Family Support Services

### What is the service?

Families with members who have disabilities face numerous challenges. Meeting the needs of a child, parent, or other family member who requires support and assistance to accomplish day to day activities can be an enormous stressor for a family. In addition, families with disabilities often face isolation, lack of resources, and discrimination. In response to these challenges, many families with disabilities have become leaders in the field of family support, not only advocating on behalf of their own members and other families, but providing peer to peer family support and playing significant policy roles in their communities and at the state and national level.

Families need support and information while learning how to best support their loved ones who are living with special needs. The family member may need a variety of therapies and services, from physical, occupational, or speech therapy, to special equipment such as wheelchairs, walkers, adaptive computers, or other services. The individual and the family may benefit from respite, formal and informal family support services, counseling, financial planning advice, mental health and other services.

Several organizations in Washington State provide peer support to parents and siblings of children and youth with special needs and disabilities. Some organizations provide one-to-one peer matching, involvement in ongoing support groups or periodic social or educational gatherings. See also the *Care Coordination* chapter for additional family services provided by public agencies.

### How/where is the service provided?

#### One on One Support:

##### **Washington State Fathers Network** <http://www.fathersnetwork.org/>

- Serves fathers, families, and care providers of children and youth with special needs through resources, support groups, social events, website, regional and state conferences, and newsletters: all events and information services are especially “dad-friendly.”
- Fathers Network is a program of the Kinderling Center, and is funded by the Children with Special Health Care Needs (CSHCN) Program, Washington State Department of Health; the Paul G. Allen Charitable Foundation, and through private donations.

##### **Washington State Parent to Parent** <http://www.arcwa.org>

- Serves families of children and youth with special needs throughout Washington in a variety of ways, including Parent to Parent peer support and matches, website, resources, and other activities. Helps families make connections with other families whose children have a similar condition and/or are from a similar ethnic background.
- Washington State Parent to Parent is a program of the Arc of Washington and works closely with CSHCN Coordinators, medical home teams, feeding teams, and other

services provided by Washington State Department of Health CSHCN Program. CSHCN Program also provides funding.

- **Sibling Support Project** <http://www.thearc.org/siblingsupport/>  
The Sibling Support Project is a national project for brothers and sisters of people with special needs. “Sibshops”, workshops which provide peer support for siblings of children and youth with special needs, are available through Children’s Hospital in Seattle. Generally, the children who participate are ages six to thirteen. ibKids and SibNet are free email listserves.

## **Resource and Information Services:**

### **Adolescent Health Transition Project (AHTP)** <http://depts.washington.edu/healthtr/>

- Provides information and resources to help youth and young adults with special needs transition to adult health care. Provides information on other services necessary for successful transition to all aspects of adult life. The Washington State Adolescent Health Transition Resource Notebook is a great resource available on the website.

### **The Arc of Washington** <http://www.arcwa.org/>

- Promotes the education, health, self-sufficiency, self-advocacy, inclusion and choices of individuals with developmental disabilities and their families, including serving as manager for the Washington State Developmental Disabilities Endowment Trust Fund. Resources and information available for youth and adults as well as children.

### **Washington Parents are Vital in Education (PAVE)** <http://washingtonpave.org>

- Bi-lingual/bi-cultural staff work with families, individuals with disabilities, professionals, and community members in all walks of life and with all types of disabilities. Maintains a free lending library of books and video tapes, a quarterly newsletter (PAVE Pipeline), a toll-free telephone number, free and low cost materials in a variety of formats and languages, and provides a variety of training and programs.

### **Family Educator Partnership Project (FEPP)** <http://www.arcwa.org>

- In many school districts in Washington, FEPP creates partnerships between families, educators, and community agencies in order to support children and youth who need special education services.
- Partnership Team Training promotes shared leadership within a school district to bring positive, proactive approach to planning services for children with disabilities.

### **National Family Voices** <http://www.familyvoices.org>

- Family Voices is a national, grassroots clearinghouse for information and education about the health care of children with special needs. Their belief in the strength of families is

inspiring: “We all come from families. Families are big, small, extended, nuclear, multi-generational...families have strengths that flow from individual members and from the family as a whole.”

## **Eligibility**

All families are eligible and welcome to access support and resources, regardless of income, age, ethnicity, or other demographic features. Some programs are targeted to specific populations, for instance siblings, or fathers.

## **Who is receiving the Service?**

We don't have routinely collected data on how many people are receiving family support services, but we know that there are approximately 211, 000 children with special health care needs in Washington State. About 177,000 Washington State households include a child with special health needs.

## **Issues/Concerns**

- Family support is an essential feature of caring for children and youth with special health care needs. It should not be limited to income eligibility criteria. All families, regardless of income, education, geographical location, and other demographics, need support.
- Culturally competent family support for ethnically diverse populations is inadequate. Trained ethnic outreach coordinators and cultural brokers are needed to provide better services for families from culturally diverse backgrounds. Funding is needed to make this happen.
- Providers, including doctors, case managers, school nurses, and teachers benefit from knowing more about family support services available. When professionals know what is available, they are more inclined to refer families to support.
- Family centered care and support comes through partnerships between families and professionals. Partnership between families and providers is an important area for continued work and development.

The list of organizations in this document is an overview of major sources of support and information. For more information, see the document “Starting Point,” available at <http://www.cshcn.org>.